

Hello and thank you for the opportunity to discuss some of my concerns about health information exchange. To briefly introduce myself, for most of my professional years I worked as a systems and software engineer for fortune 100 companies mostly in telecommunications. I am here today to describe what I believe is important related to electronic health information exchange and privacy. My extensive technology background leads me to a very different opinion about this topic than you may hear from others.

Privacy and HIPAA are cited as reasons why electronic exchange of health information should not be done or limited. This is a red herring. As a patient the first thing I am always required to do is to sign a form giving the health care provider the ability to send my health information to an insurance company so the provider can get paid. If they aren't paid, that form lets them send the information to a collection agency.

Here's reality. I was evaluated by a Neuro psychologist on multiple occasions, and he would only give his reports to my primary care doctor. He would not give them to me. These reports contain lots of very detailed private information about me, sexual behavior, my emotions, and my concerns. They also included information about finger tapping and the grooved pegboard test for fine motor control, and later those would be crucial. Multiple times I was referred to specialists for different reasons. Each time I asked the Neuro psychologist to fax the reports to the physician I was going to see. I knew these were faxed over unsecured, ordinary fax lines. Most in health care don't even know what a secure fax line is. I would get to an appointment, after waiting 3 months or more, and the doctor did not have the reports. I finally started insisting that I be given copies of the reports that I could carry with me. There were at least four different occasions when I showed up for an appointment, the neuro psych report was supposed to have been faxed, and the doctor said they did not receive anything.

These neuro psych reports held extensive, subjective information about me including the evaluator's critical perceptions of my psychosocial mal-adjustments and his notions about my inadequacies as a human being. I do believe that the psychologist did fax the reports, yet repeatedly, they were never received. I have no idea what actually happened to the faxes. I suspect that because the doctor I was to see did not have me as an existing patient, the reports ended up in a pile next to the fax machine. For all I know those reports could have been sold to Julian Assange to be posted on Wiki-leaks. Repeatedly they were sent, and did not reach the intended destination. What is done now largely uses unsecured fax lines, and unexpected, unrecognized transmissions probably are not even shredded. I'm willing to bet that most offices toss them in a recycle bin.

I have had similar experiences with test results for blood work, reports from neurologists, and medical record notes. Sometimes the neurologist's report would be saying that I was neurotic or otherwise of doubtful sanity, and I probably still am, but the reality was these reports would be faxed, and when I would show up for an appointment, they didn't have it. The only reason the appointment could continue, was that I learned to always make sure that I had copies of test results, reports, and doctor's notes in my hand which I could give to the doctor I was seeing.

Those test results disclosed all kinds sensitive intimate information, frequently with my name and social security number on them, and no one could tell me what happened to the fax. Everyone shrugged it off as if it was nothing. At the same time, detailed personal information about me was routinely sent to the insurance company so they could determine whether or not to pay for something.

Along the way, twice I had falls with a broken arm and a broken leg, each required an emergency room visit. I remember being in the middle of a very public ER area, where the intake person loudly demanded to know what medications I was on. Suddenly I was a spectacle with prying eyes all around morbidly curious to hear my answer.

I need to fast forward here. A couple years ago I was diagnosed with Parkinson's. Even in the early stages of Parkinson's the disorder changes your personality and negatively impacts your cognitive function. It is very stressful to repeatedly go to doctor's appointments and be told that you have deep seated psychological problems, and I knew in my core that's not why my hand was shaking. Parkinson's, not insanity also explained

why I had difficulty walking, and would fall ending up with broken bones. Stress makes my cognitive issues worse, my hands shake more, and sometimes I completely freeze up, I don't know where I am, how I got there, or what I'm supposed to be doing. That's in part what my service dog helps me with.

Because of my complex medical situation, I have ended up seeing many doctors. Recently I was seen by several specialists who I then asked to send reports to my primary care doctor. He was not getting those reports. When I asked if this could be done electronically, I heard things like, "Oh we don't do that." Mostly I just wanted them sent, but electronic exchanges can be encrypted and secure.

At a conference for Parkinson's patients I asked a question, "What is the best way to get coordinated care when you have to deal with multiple physicians?" The doctor who responded, said that it was up to me as the patient to make sure that all the treating specialists had the information about me that they needed to treat me. I'm not a doctor, I don't have medical training. How am I supposed to make sure that they have what they need? I deal with medication induced hallucinations of bunny rabbits, blackbirds and bugs, (Sinemet is known to trigger hallucinations) but I'm supposed to make sure the doctor has the right information. Electronic exchange gives the option of sending complete records, and it can be done with encryption so it is genuinely secure.

I worked with my primary care doctor to make sure that a complete list of all my medications was on his electronic health record system. I went for a colonoscopy which requires general anaesthesia. On the hospital's paper form, I wrote that all the medication and drug allergy information was on the doctor's system that they had access to. The intake nurse asked me if I could verbally give her the list of medications because the little room we were in did not have a terminal. She seemed genuinely put out when I insisted that she had to go look them up. Later after they gave me twilight drugs, as I was being wheeled into the procedure room, another nurse asks for my drug allergies. I have been clinically diagnosed with cognitive impairment. I am not a reliable repository for this information, nor am I a reliable transmission means. Yet clearly the expectation was that I the patient should be able to recite this information on queue.

I take so many different prescriptions that no pharmacy system automatically keeps a complete list of all of them. Yet I'm expected to be a walking repository for this information.

About a month ago I was prescribed a drug and had a negative reaction to it. My primary care doctor did not know what to tell me because he didn't have notes from the prescribing specialist, who was out of the office at a conference. I was in distress and not sure what to do. I was asking questions like, "When is it bad enough that I should go to the emergency room?" "If I go to the ER, how will they be able to get enough information about me, to treat me effectively?" The reality was, if I went to the ER, they would just be shooting in the dark trying to figure out what might be going on.

Not having a way to exchange health care information electronically makes it almost certain that I will get wrong care if I ever do need to go to an emergency room. Too many fear mongers dance with the fig leaf of privacy protection required by HIPAA to justify withholding information, while the same data are being faxed over unsecured lines to places where for all I know recipients could be posting it on the web.

I may still be a grumpy old man lacking in social skills, but this situation is nuts. We need robust electronic health information exchange. What happens now makes privacy a joke. What is being done now, does nothing to protect my privacy, really, and it does create a situation where health care professionals must just shoot in the dark. Electronic health information exchange offers that, because we are approaching privacy issues with eyes wide open, we can only make the situation better.